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ABSTRACT

Intended for educators working with children who have suffered traumatic brain injuries (TBI), this brief paper addresses parent issues, administrative issues, and programmatic issues. Noted are the five stages of adjustment typically experienced by parents: shock, elation, reality, crisis, and mourning. Professionals are encouraged to be informed on the family's pretrauma psycho-social history, to connect parents with family support groups, and to encourage family therapy. Among recommendations for school administrators are providing inservice training on TBI, documenting contacts with family members, and establishing a case coordinator system. Programmatic issues mentioned include inservice training for staff and assistance with program planning by someone knowledgeable in both TBI and school programming. Other recommendations include using an integrated team approach, developing flexible programming, and being realistic with parents regarding the student's progress. (DB)

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As those of us working with traumatically brain injured (TBI) are acutely aware, the impact of such injuries is far reaching, effecting not only the survivor, but the family, friends, school and or work involvements.

Parents of TBI survivors become parents of suddenly handicapped children and because the disability is newly acquired, they have had no preparation for it. Therefore, there is a tendency, among other things, to estimate inaccurately what is possible.

By the same token, school staff are usually inexperienced with TBI, due to its rarity in the student population. Thus, personnel may also have unrealistic or uncertain expectations (Rosen & Gerrig).

While the literature has addressed the mechanics of school reentry (e.g., placement, appropriate programming) and has also examined parenting issues, little has been written on the relationship between schools and parents, which often becomes an adversariel connection. To prevent these types of connections from occuring, we must attempt to understand the concerns and perceptions of each involved party (parents, administration and service providers) and to offer some practical suggestions for remediation.

Parent Issues

Positive school/family communication is essential to a successful school experience for a student with TBI. To achieve such a relationship, professionals involved in programmatic decisions for these students need to understand "where the parents are coming from" emotionally and what steps to take to help build a good working connection.

According to Spanbock (working manuscript) families responses to head injury can be viewed in terms of 5 stages-shock, elation, reality, crisis and mourning.

Shock occurs at the time of injury when the parents enter a medical world foreign to them and are even faced with the possibility of their child's death. Emotionally, they feel a combination of anger, pain, frustration, confusion and helplessness.

Elation occurs when their child is out of medical danger. At this point, parents tend to feel hopeful and the future looks good.

Reality sets in when the parents realize that many of their child's observed deficits may be permanent. Anger and confusion return and are joined by depression and guilt.

As time goes on and the survivor is discharged home, parents will begin to experience the difficulty of being with a head-injured individual on a full time basis. This is the crisis stage, because the changes in their child result in a constant strain on the family. Added to this is the stress of becoming the survivors' predominant social support, through loss of friends and normal social outlets.

The crisis stage should lead to a period of mourning, at which point parents begin to disengage themselves from the survivor's pretraumatic personality. However, one of the problems for schools and other involved personnel is that parents will often resist entering this stage, denying the changes and their impact on the present and the future.

School personnel need to understand these stages and the emotions and environment in which parents are now functioning. They also need to realize the situation or the needs.

Recommendations for professionals working with families

1) Access information on survivor's and family's pretrauma psycho-social history.
2) Hook up parents with TBI family support groups.
3) Encourage family therapy.

Administrative Issues

Often administrators seem to be the last to hear that a student in their district has acquired a head injury...and may not do so until a referral is made from a rehabilitation facility. At this point, many parents are still in denial and are looking to the school to provide the program (in or out of district).

It is essential that a rehab facility establish contact with

The local educational agency (LEA) as soon as possible and encourage regular communication among all 3 parties. School personnel need to understand the nature of the student's disability and treatment and be kept abreast of progress. Observation of the student by one or more school staff members should also be encouraged.

With few exceptions, LEA's have been very accommodating relative to the needs of students with TBI, often going above and beyond what is required to do. And while many parents recognize and appreciate these efforts, others, in their continuing denial, approach schools with what are perceived as being inappropriate and unrealistic demands designed to sabotage the student's program.

School personnel need to keep focused on the students' needs, which may not always be compatible with those of their parents. Often, the latter is what is ultimately addressed at PPT's, to the detrement of the student and his/her potential progress.

Recommendations for school administrators

1) Encourage school personnel to inform administration whenever they hear of a TBI related injury involving a student in their district; administrator should call parents to open the lines of communication, even if the student is still in an acute care facility.
2) Inservice staff on TBI
3) Request that rehab. staff present IEP objectives in educational terms.
4) Document every contact with family members
5) Establish the length of the PPT prior to the meeting; if more time is needed, schedule another PPT.
6) "Control" the language used by PPT members (no one should be subjected to verbal abuse). If a staff member becomes verbally inappropriate, ask him or her to leave; if a parent becomes abusive, end the meeting.
7) Provide emotional support to staff members (to help prevent burnout).
8) Establish a case coordinator to "field" phone calls, act as a liason for all involved agencies, professionals, ets. and generally coordinate team activities.

Programmatic Issues

Teachers who are about to work with TBI students for the first time, rarely ask questions about what to expect and how to handle forthcoming problems. This might be attributable, at least in part, to the fact that teachers may not know enough

to realize what they do not know and what to anticipate (Rosen & Gerring, 1986).

As recommended above, inservice training should be provided to all staff working with the TBI student. Assistance with program planning should also be provided-by someone knowledgeable in both TBI and school programming. Knowing that measures are being taken to educate the staff as to their child's needs and to insure appropriate programming should go a long way toward minimizing at lease some of parents' anxiety concerning reentry.

Other Recommendations

1) Use of an integrated team appraoch with members meeting on a weekly basis.
2) Flexiable program that would include such things as sequence of classes, length of school day, built in rest breaks.
3) Realistic approach to parents regarding student"s achievement/progress,
4) Good transition planning, including early involvement by vocational counsellor.

References

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